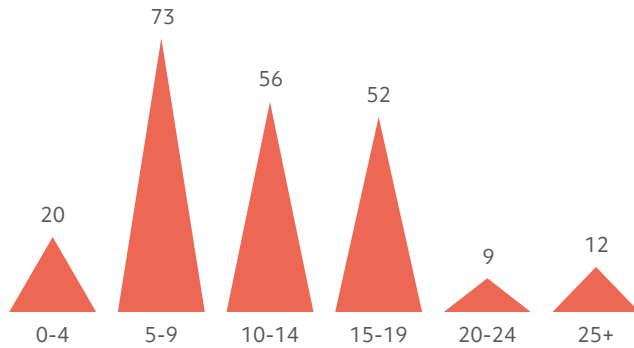


Simons Searchlight Registry Update 16p11.2 deletion

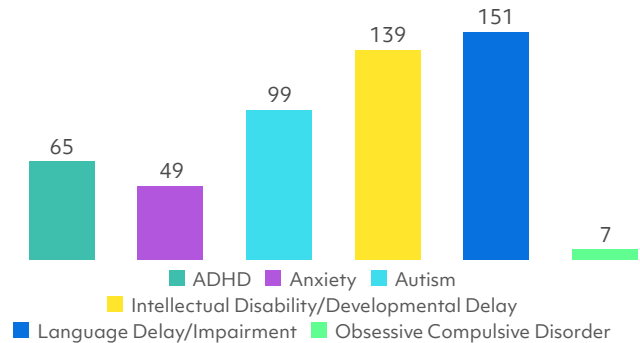
Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 222 participants with a 16p11.2 deletion.

October 2023

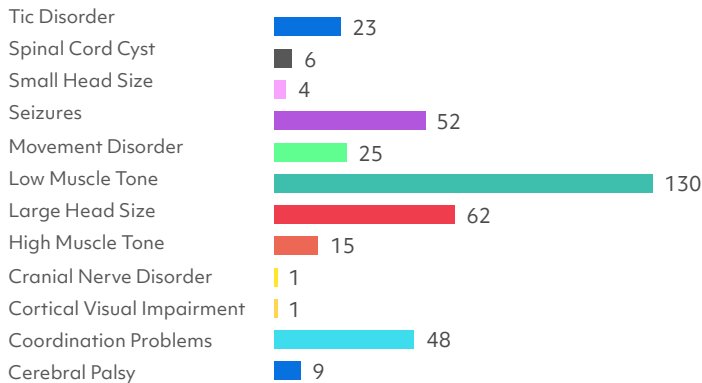
Ages in Years



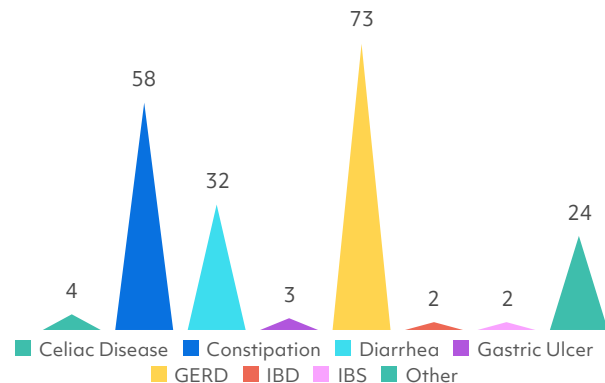
Developmental and Behavioral Conditions



Neurological Conditions



Gastrointestinal Conditions



NOTES: Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.

How to participate?

The information in this report is made possible by the active participation of the 16p11.2 deletion community! Progress for individuals in your community with 16p11.2 deletion is shown below - log in to your simonssearchlight.org dashboard today to check for new surveys and tasks. Your data could hold the clues geneticists need to find answers.



STEP 1

Sign up
online

508



STEP 2

Provide your
genetic
lab report

298



STEP 3

Share your
important
medical history

229



STEP 4

Fill out
surveys

250



STEP 5

Provide a blood
sample if you are
interested

107



STEP 6

Update us
every year

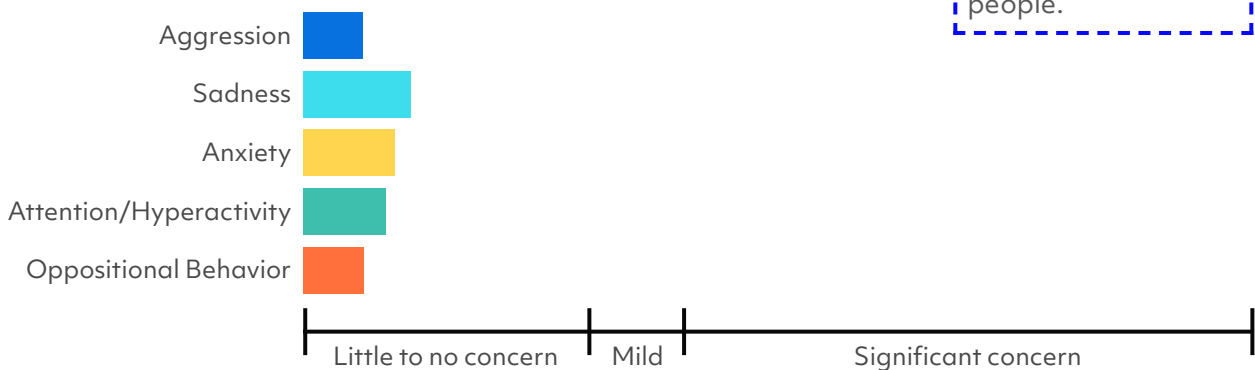
Log in to see
next steps

Information Spotlight: Child Behavior Checklist for Ages 1.5–5

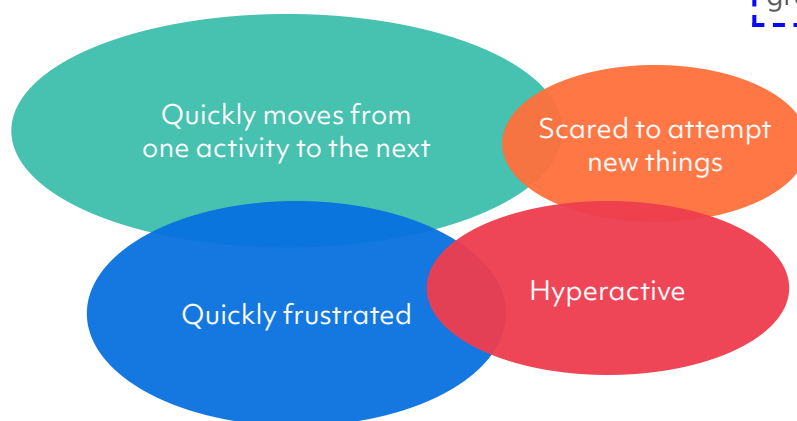
The **Child Behavior Checklist (CBCL)** is a survey used for caregivers to share their concerns about their children's behaviors and emotions.

Caregivers completed the CBCL for Ages 1.5-5 (CBCL/1.5-5) for **23** children in the Simons Searchlight **16p11.2 deletion** community.

Behavioral and Emotional Concerns Ages 1.5-5 Years (23 individuals)



Top Behavioral and Emotional Concerns Ages 1.5-5 Years (23 individuals)



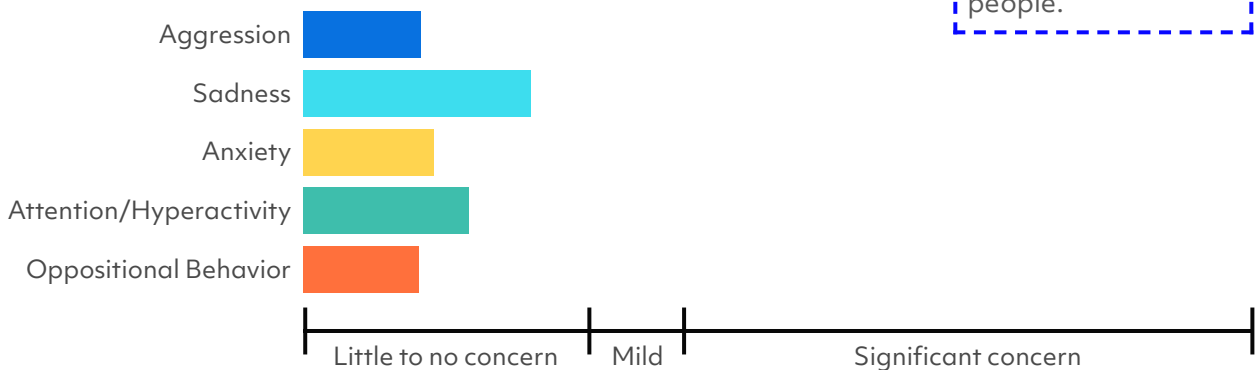
Kindly note that these summaries are from self-reported online research surveys and errors are possible. The behaviors and emotions shown may not apply to everyone, and individual caregiver perspectives and levels of concern may vary. Please contact us with any questions.

Information Spotlight: Child Behavior Checklist for Ages 6–18

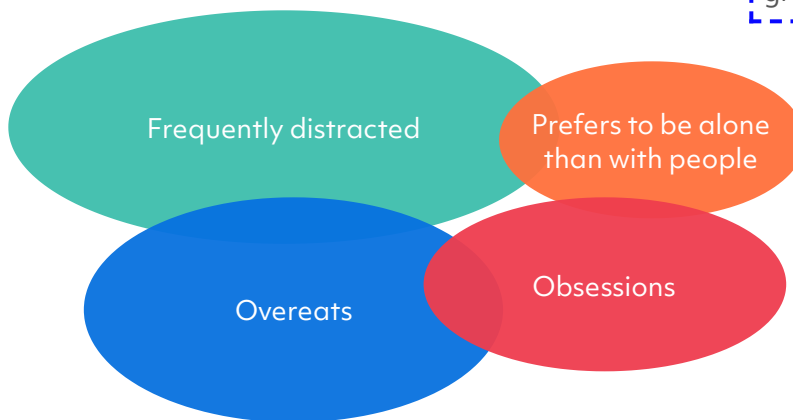
The **Child Behavior Checklist (CBCL)** is a survey used for caregivers to share their concerns about their children's behaviors and emotions.

Caregivers completed the CBCL for Ages 6-18 (CBCL/6-18) for **177** children in the Simons Searchlight **16p11.2 deletion** community.

Behavioral and Emotional Concerns Ages 6-18 Years (177 individuals)



Top Behavioral and Emotional Concerns Ages 6-18 Years (177 individuals)



Kindly note that these summaries are from self-reported online research surveys and errors are possible. The behaviors and emotions shown may not apply to everyone, and individual caregiver perspectives and levels of concern may vary. Please contact us with any questions.